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Vulvodynia: A disease commonly hidden in plain sight

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Vulvodynia is a poorly recognized entity by clinicians – even by those who deal with female sexual health. While the study of vulvovaginal diseases, including pain disorders, is included in most residency programs in North America, it is acknowledged that clinical exposure may be insufficient. The scenario in the rest of the world is probably no better [1].

Vulvodynia affects at least 6% of women (up to 20% in some series), and can be found at any age and in all ethnic groups [2,3]. The disease is common and dramatically affects quality of life, beyond the obvious sexual aspect [4]. The importance of investigating vulvar symptoms even in younger women is underlined by studies reporting that the prevalence of vulvodynia among adolescents is similar to that among adult women [5].

The International Society for the Study of Vulvovaginal Disease (ISSVD) defined vulvodynia as vulvar pain of at least 3 months' duration, without clear identifiable cause, which may have potential associated factors– or, more simply, idiopathic vulvar pain [6]. It was subdivided according to location (generalized, localized) and the need of a stimulus to elicit the symptoms (provoked, spontaneous, or mixed). In the terminology recommended in 2015 it was acknowledged that there are potential associated factors [7].

The diagnosis of vulvodynia is one of exclusion, albeit pretty straightforward. Detection of localized sensitivity in the vulvar vestibule, by using a swab, may uncover the problem. For some women, having a diagnosis, a name for the disease, is highly relieving – they commonly report that they felt the symptoms were not valued by health care providers, or that their condition was considered to be fake, exaggerated, or merely psychological. Interestingly, it has been shown more generally that there is a sex bias when evaluating pain – women's pain tends to be less valued [8–10]. After the diagnosis of vulvodynia is made, it is fundamental to establish realistic goals, keeping in mind that some of these women have been suffering for months or years. Women must know in advance that the path to recovery will have its ups and downs, and that significant improvement, rather than cure, is the objective.

Failure to make a proper diagnosis often leads to irrelevant or deleterious diagnostic exams (e.g. biopsies, HPV testing) and treatments (e.g. imiquimod, LASER, trichloroacetic acid, embolization [11]). Vulvodynia has several different aetiologies and associated conditions, and thus different – and unpredictable - responses to treatment. The placebo effect is very high in the treatment of vulvodynia and sexual dysfunction (vulvodynia is a cause of sexual dysfunction, rather than a sexual dysfunction itself) [12–14].

When dealing with vulvodynia patients, the *primum non nocere* principle must be kept in mind – in case of doubt, referral to a provider or a team with experience in the field is advisable. Despite the usually low levels of evidence supporting any particular intervention, treatment measures include stopping unnecessary topical medication, topical lidocaine, anticonvulsant and antidepressive drugs, and physical therapy [14–16]. Some women, however, will fail to improve and, in selected cases (vestibulodynia), some will be candidates for surgery (vestibulectomy). This is a last resort and should probably be performed only in referral centres.

The lack of standard measures of treatment outcome prevent even partial comparison of clinical trial results in vulvodynia [17].

The definitions are clear and the diagnosis is not difficult. Given that, two questions naturally ensue: "why is it not diagnosed more often?" [8] and "what can we do to improve it?"

Since the first description of vulvodynia, which goes back, at least, to the 19th century, it has had several other designations, some of which are still frequently encountered in the scientific literature, such as "vestibulitis". This is a clear example of a misleading designation, since clearly it is not an infectious or inflammatory disease. The use of several different designations for the same condition, as well as the inaccuracy of some of them, coupled with the lack of proper definitions, may have slowed investigation in this field.

Some women consider that it is normal to have pain during intercourse. Others tend to attribute the symptoms to other, better-known conditions, or simply feel ashamed of their symptoms [8]. Too often, it is assumed that genital pain, burning, or pruritus are due to candidosis – which is known to be wrong most of the time [18]. On the other hand, medical knowledge of the condition may be insufficient or there may even be some prejudice – in one study, 45.1% of women with vulvodynia felt they were being stigmatized (somatization, excuse to avoid sex) by the health care provider [8,19].

Women with vulvodynia often are incorrectly categorized as having "vaginismus", which does not necessarily imply pain. "Vaginismus" disappeared from the *Diagnostic and Statistical Manual of Mental Disorders, 5th Edition*: along with dyspareunia, it became

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part of the broader concept of genito-pelvic pain/penetration disorder (GPP/PD) [20]. It became one entity, without acknowledging the differences or the existence of vulvodynia. Following the publication of this manual, most women with vulvodynia may be misclassified as having GPP/PD and be offered only psychological treatment. While vulvodynia may indeed be sometimes associated with psychological sequalae and sexual dysfunction – which definitely can benefit from a psychological approach – failing to recognize there is a somatic cause for the symptoms can add to the suffering of the woman [21,22]. Therefore, vulvodynia should also be studied in residency programs of psychiatrists/sexologists, as well as in the graduation programs of other mental health professionals. Women currently classified as having genito-pelvic pain/penetration disorder should always be evaluated by an experienced physician trained in vulvovaginal diseases and/or pelvic floor disorders.

The diagnosis of vulvodynia is still often missed. The responsibility is of both patients and health care providers. Education is the key to change this scenario: it is mandatory to increase the awareness of both parties. We must learn how to address sexual health issues and how to make patients feel safe and comfortable discussing them.

Our inability to correctly manage vulvodynia derives from a lack of awareness. It is, however, an unfair game: when a cause is identified for the pain, the condition is no longer called vulvodynia but rather vulvar pain caused by a specific disorder, and a specific treatment can be implemented.

The management of vulvodynia is difficult and often frustrating to both parties, but we have no excuse to misdiagnose it. We may not cure all patients, but we can make a difference in the life of most – and those cases are rewarding. Chronic pain or burning must ring this bell….

Contributors

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